#### Physician's Cancer Reporting

REPORTING CANCER CASES TO THE

VIRGIN ISLANDS CENTRAL CANCER REGISTRY

United States Virgin Islands
Central Cancer Registry



### What is a Central Cancer Registry?

central Cancer Registry is a reliable and updated source of information for research on cancer and its causes. A cancer registry is an epidemiologic surveillance system to collect information designed regarding incidence, distribution, risk factors and mortality of the disease. This information is essential to public health professionals, researchers, the medical community, and policy makers to understand and address the cancer burden. This information is acquired through active reporting of data for cancer cases and central nervous system neoplasms in places where these patients are diagnosed or treated.

The United States Virgin Islands Central Cancer Registry (USVI-CCR) is part of the Department of Health (DOH) - Chronic Disease Prevention Program (CDPP). Beginning on January 1st, 2016, the USVI-CCR will start the collection of cancer cases. Reportable cancer cases diagnosed and/or first course of treatment done at your facility on and after this date must be submitted to the Central Cancer Registry. The collaboration of each healthcare provider in the USVI is of vital importance to achieving a successful Central Cancer Registry implementation that will result in great benefit to our community.

# Act No. 6286 from 1999: To establish a Cancer Registry for the Territory of the Virgin Islands

he reporting of cancer cases by health care professionals is required by law since 1999. Act No. 6286 establishes that: "each health care facility diagnosing or providing treatment to cancer patients shall report each case of cancer to the Commissioner in a format prescribed by the Commissioner...".



Even though there has been a law requiring cancer reporting, there has been no law enforcement since the enactment of the law. The goal for the DOH is to have a fully functional Central Cancer Registry with a reference date of January 1st, 2016. The DOH will endeavor to inform healthcare providers and answer any questions they may have regarding data collection.

It is the main goal of the USVI DOH to have a Central Cancer Registry with accurate and updated data. It is also expected to have data that can be used for research, and data that can be published nationally. To achieve all these goals, information to be collected must comply with the standards, guidelines and data requirements established by the Centers for Disease Control (CDC) - National Program for Cancer Registries (NPCR).

#### Why physician's offices must report cancer cases?

Recent changes in cancer diagnosis and treatment from hospital to ambulatory healthcare settings are increasing the importance of non-hospital healthcare providers' data for cancer surveillance, especially in certain tumors that are primarily seen in an outpatient setting, such as, hematopoietic diseases, early stage melanoma, prostate, colorectal, and breast cancers. In addition, sometimes the physician is the only source of information when a patient is diagnosed at the office and then elects to pursue treatment off-island.

## Reportable Diagnoses



- Invasive and in situ malignancies and VIN III, VAIN III and AIN III.
- Borderline and benign primary intracranial and CNS tumors
- Lymphoma, leukemia, and other malignant blood disorders (chronic myeloproliferative diseases, and myelodisplastic syndromes)

#### The following malignancies are **NOT REPORTABLE**:

- Basal Cell and Squamous Cell Carcinoma of the skin (unless it is occurring in the genitalia and vermillion of lips)
- Carcinoma in situ or intraepithelial neoplasia grade III of the cervix CIN III) and prostate (PIN III).

\*\*\*If you have any question about determining reportability, call the USVI-CCR for assistance.\*\*\*

#### **HIPAA & Cancer Registry**



he Health Insurance **Portability** and Accountability Act (HIPAA) allows the divulgation, without individual authorization, to health **authorities** public the allowed by law to collect and receive this information with the purpose of disease control and prevention. HIPAA is not an obstacle for any local act that mandates the

disease reporting for public health purposes. For more information regarding this theme please visit:

http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm.

#### Report your cases in 3 easy steps...

- 1. Identify the patient with a definitive diagnosis of any of the reportable diseases listed in the Reportable Diseases List.
- 2. Complete the Physicians Reporting Form the form can be completed by either printing and filling out the form (information must be legible) or using the PDF fillable format available under the **Forms & Applications Section** on the DOH webpage www.healthvi.gov (preferred method).
- 3. Send it to the USVI-CCR completed forms may be sent over fax to 718.9505 or via encrypted email (described later in this document) to viccr@doh.vi.gov (preferred method).

### United States Virgin Islands Central Cancer Registry Physician's Reporting Form\*

Physician's Office Information									
Facility Physician				Address					
Name	Name Name			Address			5		
Patient's Information									
Last First							Middle		
Name Name				Name					
Address (please include Estate, City, State, Zip)									
Social Security	Date of Bi	rth	MRN:	Health Insurance					
Race:   Caucasian / White   Black   Asian   Native American   Other   Unknown  Hispanic:   Yes   No   Other									
Marital Status:  Sex:   Male   Female   Other:   Other:									
Cancer Information									
Date Diagnosed (m	ate Diagnosed (mm/dd/yyyy): Where diagnosed			J\$		Primary Site (where tumor arose):			
Paired Organ: 🗆					Histology:				
- If yes, specify: □Right □Left □ Bilateral □ Unknown									
Behavior: Diagnostic confirmation (check one):									
□ Benign □ Borderline □ In Situ □ Malignant □ Histology □ Cytology □ X-ray □ Clinical □ Unknown									
Grade (check one): ☐ Well differentiated ☐ Moderately differentiated ☐ Poorly Differentiated ☐ Undifferentiated ☐ Unknown									
Stage (check one): □In Situ □Localized □Regional by direct extension □Regional to LN □Regional direct & LN □Distant □N/A									
TNM: T N M Stage □ Clinical □ Pathological □ Not Applicable									
Endoscopy findings:									
Tumor Markers Results (example: CA 19-9, CA 125, CEA, CGA, HPV, LDH, ER, PR, Her2/neu, KRAS, AFP, PSA, hCG, etc.)									
Treatment Information									
		Type / Desc	cription		Dat	te	Where performed		
Surgery									
Radiation									
Chemotherapy									
Hormone									
BRM									
Other									
Follow Up / Patient Status				Completed by:					
Date of last contact:				Name:					
Vital Status:   Alive Dead									
Cancer Status: □ evidence of CA □ no evidence of CA If expired; please provide date and place of death:				Date:					

In order to protect our patient's privacy and to comply with HIPAA regulations the attached forms must be encrypted and password protected using an encryption software. Microsoft encryption is not recommended.

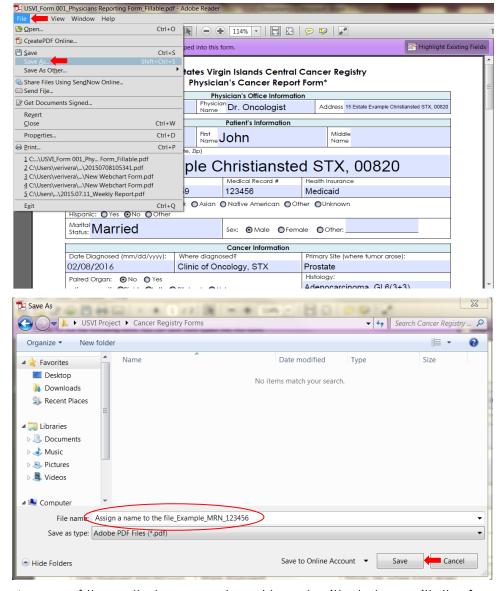
<sup>\*</sup>This form is intended for physician office setting ONLY. Not for hospitals or healthcare clinics.

<sup>\*\*</sup>Please, send the completed form to the USVI-CCR via e-mail to: viccr@doh.vi.gov

PHYSICIAN'S CANCER REPORT FORM INSTRUCTIONS						
	For a 19th of the form of the con-					
Departing Equility	Facility Information					
Reporting Facility	Record the complete name, address, and telephone number of your facility or physician's office.					
	Patient Information					
Patient Name	Record the patient's full name.					
Patient's Address	Record patient's permanent home address at time of diagnosis, not a temporary relocation for treatment. Street address takes priority over post office box number.					
Social Security Number	Record the patient's social security number. Do not record a spouse's number.					
Date of Birth	Record patient's birth date in MM/DD/YYYY format.					
Medical Record Number	Record the patient's medical record number					
Health Insurance	Record the patient's health insurance					
Race	Check off the patient's race.					
Hispanic	Check off whether the patient considers himself or herself to be of Hispanic origin.					
Marital status	Specify patient's marital status at time of diagnosis					
Sex	Check off the patient's sex/gender.					
	Cancer Information					
Date of Diagnosis	Record the date the patient was first diagnosed with cancer by a recognized medical practitioner.					
<u> </u>	Record in MM/DD/YYYY format. If unknown, record "unk".					
Where Diagnosed?	If the patient was diagnosed elsewhere, record the facility name and location. If unknown, record "unk".					
Primary Site	Record the site of origin of the tumor. Record the subsite if known (ie. UOQ breast, LL lung). If unknown, record "unk". It is important to identify the primary site and not a metastatic site.					
Paired Organ	If the site of origin is a paired organ, check the laterality.					
Histology	Record the histologic cell type of the tumor (ie. mucinous adenocarcinoma; infiltrating ductal CA					
Behavior / Grade	Check off the behavior/grade of the tumor.					
Diagnostic Confirmation	Check off the most reliable method used in diagnosing this cancer. Attach copy of pathology report.					
	Use the following guidelines to determine the method:					
Please, attach copy of	Histology: Microscopic diagnosis based on tissue specimens (ie. biopsy, frozen section, and surgery).					
pathology report.	Cytology: Microscopic diagnosis based on cells rather than tissue (ie. smears from sputum, bronchial)					
	washings, brushings, fine needle aspirations, etc.)					
	Clinical: Diagnosis not supplemented with positive microscopy (ie. made at surgical exploration, by					
	use of an endoscope or physician's statement that patient have cancer).  • X-ray-Radiological diagnosis (x-rays, scans) not microscopically confirmed.					
	<ul> <li>Unknown: diagnosis method is unknown.</li> </ul>					
Ctaga 2	Check the stage of tumor at diagnosis (extent of disease within four months of diagnosis).					
Stage	Use the following categories to determine the extent at diagnosis:					
	<ul> <li>In Situ: tumor has not progressed through the basement membrane of the organ involved.</li> </ul>					
	Local: limited to site of origin; progressed through the basement membrane but not beyond the					
	walls of the organ involved.					
	Regional - Direct Extension: direct extension to adjacent organs or tissues.					
	Regional - Lymph Nodes: involvement of regional lymph nodes.					
	<ul> <li>Distant: direct extension beyond adjacent organs or tissues, or metastases to distant sites or distant</li> </ul>					
	lymph nodes.					
	<ul> <li>Unknown: no information is available to determine extent of disease.</li> </ul>					
TNM	Record the stage according to the AJCC. Specify if it is a clinical or pathological staging.					
Tumor Markers	Record any result from tumor markers tests done to the patient during work up.					
	Treatment Information					
Treatment	Record all first course treatment that the patient received. Do not record second course treatment.					
	First course treatment includes all cancer-directed treatment modalities given by clinicians at the time of					
	diagnosis. When recording treatment, write the type of treatment, the date the treatment was received o					
	began and where performed.					
	Follow Up / Patient Status					
Date Last Seen	Record the date the patient was last seen or date of death in MM/DD/YYYY format.					
Vital Status	Check the vital status of the patient as of the date last seen.					
Cancer Status	Check the patient's cancer status as of the date the patient was last known to be alive or dead.					
If Expired, Place of Death	If patient expired, record the place of death. If unknown, record "unk".					
Cause of Death	If patient expired, record the place of death. If unknown, record "unk".					
Cause of Dealit	in patient expired, record the eduse of death. If otherwis, record othe.					
Completed by						
Form Completed By	Record the full name of the person completing the form.					
Date Completed	Record the date completed.					
	6					

#### Saving PDF Fillable Format Forms

1. Once a cancer case has been identified, please complete the Physicians' Reporting Form. The form included in this document can also be downloaded from the DOH Website in a PDF fillable format. This simplifies the process by allowing typing of the information directly into the form. If you have any question filling out the form, please call 718.1311 ext.: 3198 / 3037 /3100. Note: If you are completing multiple forms, you must <u>Save As</u> every form to avoid losing information. (Click File > Save As > Assign a name to the file > Click Save)
After saving the form, you will be able to start a new one. Be careful not to save the form with already existing file names, otherwise you will be overwriting an existing document and losing information.



- 2. A copy of the pathology report must be submitted along with the form.
- 3. The forms can be submitted either by:
  - a. Encrypted e-mail. For instructions on encrypting files please, read the "Encrypting Files before Sending Data to the CCR" section.
  - b. Fax: send the completed form and pathology report to 340.718.9505

#### Encrypting Files before sending data to the Cancer Registry

Data encryption is the process of converting data from a plain-text, or readable, form into a form that can be understood by the sender and the intended recipient, and no one else. Encrypted data usually looks like a long sequence of random letters and numbers. The intended recipient of the data has the key or unique way to change the data from its encrypted form back into plain text.



Encryption is a critical component of

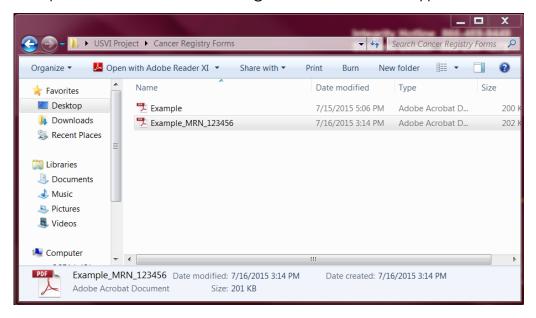
data security. It ensures that if the data is accessed by an unauthorized person, he or she will not be able to read it and thus cannot misuse it.

The software 7-zip available for free at: <a href="http://www.7-zip.org/download.html">http://www.7-zip.org/download.html</a> can be used to compress and encrypt files.

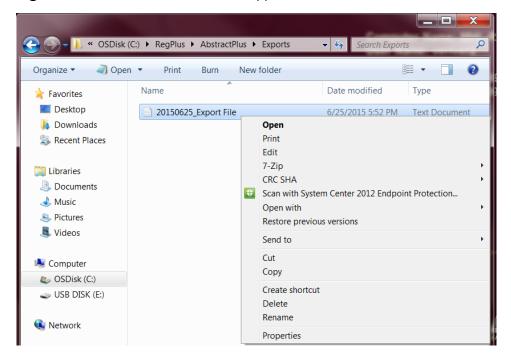
"Introduction to Data Encryption." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, 13 Jan. 2015. Web. 26 June 2015. <a href="http://www.cdc.gov/cancer/npcr/tools/security/encryption.htm">http://www.cdc.gov/cancer/npcr/tools/security/encryption.htm</a>.

After the Physicians' Reporting Forms are ready to be submitted to the CCR, an encryption process must take place to secure the PHI included in each form. Failing to do this will result in a data security breach. To encrypt a file, 7-zip (or other encryption software) must be installed on your computer.

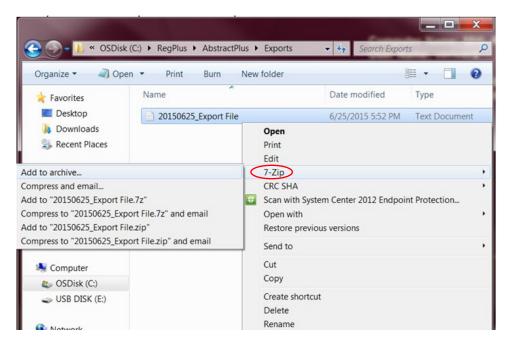
1. Open the folder containing the file to be encrypted.



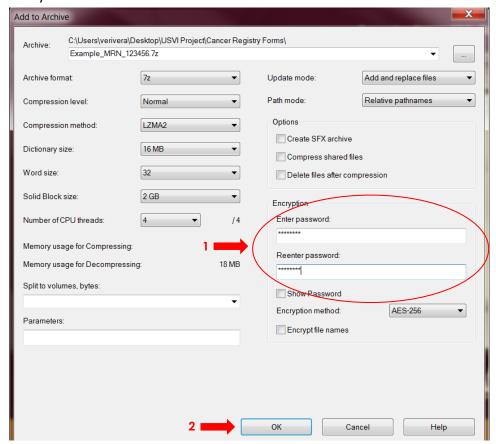
2. Right Click the file to be encrypted and from the menu select 7-zip.



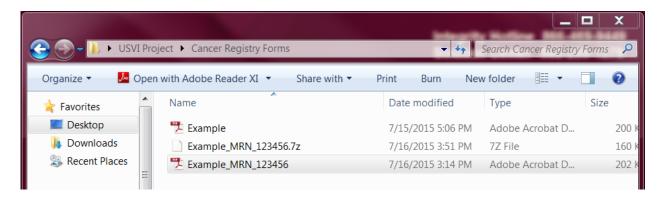
3. Once you select 7-zip, select the option Add to archive.



4. The following window will open. Complete the Enter password field. Make sure to enter a safe password (do not use phrases like: password, 123456, etc.). Click **OK.** 



5. A new file will be created in the folder with the extension .7z.



The file is ready to be sent as an email attachment. Multiple documents may be selected and encrypted in one folder.

When attaching a document to an email, make sure that the selected file is the encrypted (.7z) file!!!

- 6. Send the email with the encrypted attachment to: viccr@doh.vi.gov.
- 7. Call to the USVI-CCR authorized person to provide the password. Never send the password via email.

#### Cancer Registry Terms

Abstracting: The process of collecting and recording pertinent cancer data from a health record.

Cancer Registrar: Cancer data management professionals who collect, abstract, and report cancer statistics for or to various healthcare agencies

Case Report: A detailed report of the diagnosis, treatment, and follow-up of an individual patient. Case reports also contain some demographic information about the patient (for example, age, gender, ethnic origin).

Reference Date: starting date established for a registry, usually January 1 of a given year, after which all cases diagnosed or treated at the facility, regardless of date of initial diagnosis, must be entered into the registry.



# VIRGIN ISLANDS DEPARTMENT OF HEALTH CHRONIC DISEASE PREVENTION PROGRAM VIRGIN ISLANDS CENTRAL CANCER REGISTRY

Webpage: www.healthvi.gov

Email: viccr@doh.vi.gov

Phone: (340) 718-1311 ext. 3198 Fax: (340) 718-9505